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joint improvement team



The Dementia Services
Development Centre



Telecare and physical disability

Using telecare effectively in the support of people with severe physical disabilities and long-term chronic conditions

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Preface

This book explores how telecare can contribute to the support, protection, and quality of life of people with complex physical disabilities and some disabling long-term conditions. It also considers the importance of telecare in providing support and reassurance to carers.

This is one of a number of publications funded by the Scottish Government's National Telecare Development Programme², in pursuit of the strategic goal of raising awareness of the importance of telecare in contemporary health and social care services. The other books in this series are:

- Telecare and dementia – using telecare effectively in the support of people with dementia
- Telecare and sensory impairment – using telecare effectively in the support of people with sensory impairments
- Telecare and learning disability – using telecare effectively in the support of people with learning disabilities

The books are written for assessors, care and support staff and their managers, telecare service managers and development staff. Senior managers should also find them useful in informing service planning, and they should help raise awareness, expectations and generally advance understanding among service users and carers.

Each book also contains case studies and a training programme intended to help trainers when designing both awareness-raising and skill-development programmes. Programme directors responsible for basic and post-basic programmes for nurses, social workers or occupational therapists should consider these as a sound basis for a module on telecare.

Examples of equipment which might contribute to the safety and quality of life of the person utilising telecare are featured in each book. The aim is to support readers by providing information on some of the wide range of telecare products available. The books do not endorse any specific product or supplier, but provide examples of what is currently commercially available or emerging on to the market. Where possible, details of suppliers/manufacturers have been provided at the end of each book.

As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life.

1: Introduction

We all rely increasingly on technology in almost every aspect of our lives. Within our homes, devices such as microwaves, DVD players and flat screen TVs enhance the quality of our lives and reduce the amount of time we spend on the drudgery of housework. We rely on computers and mobile phones for information, social contact and entertainment, and to help us make informed choices about purchases and services. Away from home, technology such as GPS (global positioning systems) and satnav (satellite navigation) – often incorporated into our mobile phones – has the potential to guide us, keep us in touch, and keep us safe.

People who are more vulnerable and dependent because of a physical disability ought to have the same access to, and benefits from, this increasingly cheap and accessible technology. As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life. It can also overcome some of the limitations of specific conditions. One purpose of this book is to raise awareness of these issues and provide practical guidance on how to introduce technology to potential service users.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community³, also requires us to maximise the benefits of technology. There is now plenty of evidence to show that telecare can release significant resources from within health and social care systems and facilitate changes in the balance of care⁴. It also has the potential to improve important outcomes such as independence and feelings of safety.

This book will outline how telecare can contribute to improved outcomes for service users. It includes sections on:

- definitions of telecare (along with the related concepts of telehealth, assistive technology, environmental controls, and telehealthcare)
- the importance of good needs and risk assessment if telecare is to help meet those needs and manage those risks
- ethical dilemmas and how these can be resolved
- how needs may be met using telecare as part of a package of care and support
- issues particular to carers
- case studies and an outline training programme

Definitions: what is telecare?

In this book the term telecare is used to describe the use of equipment within and outwith the home to monitor changing needs and risks, and to provide alerts and information that enable improved and informed responses to those needs and risks.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community, requires us to maximise the benefits of technology.

The definition below is the one used in the National Telecare Development Programme in Scotland. It forms part of the 'shared vocabulary'⁵ agreed and published by the Scottish Government, and is consistent with definitions used in the English and Welsh development programmes.

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years.

Telecare is the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards.

First, second and third generation telecare

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years. The following informal classification, based on 'generations', provides a way of distinguishing between different stages of development and application.

First generation telecare refers to equipment that forms part of most community alarm services. It is used to describe user-activated alarm calls (by push button, pendant or pull cord) to a control centre where a call handler can organise a response of some kind. This is usually via a neighbour, relative or friend acting as a 'key-holder'.

Second generation telecare evolved from the introduction into basic community alarm services of sensors such as smoke, gas, heat and flood detectors. Second generation telecare now includes sensors which can monitor not just the home environment, but aspects of lifestyle, physiological measures and vital signs. These sensors can collect and continuously transmit information such as when doors are opened, whether taps are running and the use of electrical appliances. Through passive infrared sensors (known as PIRs), movement both within and outwith the home can be detected. This provides much more sophisticated and comprehensive support for managing risk and improving quality of life. Second generation telecare can also be used to provide data about someone's lifestyle, movements and routines, which can be used for needs assessments.

Third generation telecare developed from improved and increased availability of broadband, wireless and audio-visual technology. It offers the potential for virtual or tele-consultations between the service user and their doctor, nurse or support worker, thus reducing the need for home visits or hospital appointments. Furthermore, it provides increased opportunities for people (particularly those unable to leave their homes alone) to 'visit' libraries, shops and maintain contact with family and friends.⁶

Telehealth

In this book the term telehealth refers to the use of monitoring and measuring devices to collect information about vital signs (such as temperature, blood pressure and blood sugar level), symptoms or health conditions in the patient's

home. This information can then be transmitted from the device to a call handler, nurse, or other clinician, who can then advise the patient by phone, text or email on how to manage their symptoms and condition. Clinicians can be alerted to significant changes in a patient's condition, and the patient advised or reassured appropriately. This can take place without the need for a home visit, visit to a surgery, or other consultation. Telehealth is often used to enable people to manage chronic conditions, for example high blood pressure or diabetes.

Telehealthcare

The Scottish Government has published a paper on long-term conditions⁷ which includes a definition of telehealthcare, illustrating how this term emphasises a holistic approach to the person, who should be at the centre of the service:

There is increasing convergence between telehealth and telecare, with the introduction and expansion of remote monitoring as part of the 'telehealthcare' package available in a person's home. Telehealthcare offers a range of care options remotely via phones, mobiles, broadband and videoconferencing. It can improve the patient's experience of care by reducing the need for travel to major cities and hospitals to receive care and treatment. It has been used successfully to provide treatment for dermatological, cardiac and neurological conditions. It enables care to be delivered in remote communities, allows GPs to consult specialists remotely to avoid unnecessary referrals and enables networks of learning for clinicians and maximisation of skill mix for teams.

Assistive technology

Assistive technology is another collective term for devices for personal use designed to enhance the physical, sensory, and cognitive abilities of people with disabilities to help them function more independently.

Environmental controls

Environmental controls are equipment systems that enable people with higher levels of physical impairment or chronic health problems to control access to their home, to summon emergency help and to operate domestic appliances. For instance, a single remote control unit can enable a wheelchair user to control temperature and open and close windows, curtains and doors (in addition to the more conventional functions of controlling TVs, DVD players, and audio equipment).

Telecare as part of a personalised service

Telecare should not be seen as the *solution*, a single one-dimensional response to needs or risk. It is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics (such scenarios will be explored later in this book). Telecare is effective when it forms part of a personalised programme or package of care and support, and is accepted as such by the service user, their informal carers and other staff/services.

Telecare is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics.

To be effective telecare requires:

- informed, skilled and personalised outcomes-focused assessment of needs and risk
- resolution of ethical dilemmas around capacity, informed consent and choice (for each individual in each situation)
- training and education for the service user, carers, personal care and support staff in how the equipment can be used or misused and how it should be tested and maintained (for example, battery replacement)

Telecare services

So far, this introduction has only discussed equipment. The term 'telecare services' sets the delivery of equipment in the wider context of health and social care services. In a practical sense, this means efficient, up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols. These staff will be available every day of the year, and will be skilled in making judgements about the information and alerts sent by the equipment, and in facilitating the most appropriate response possible. Such centres are absolutely essential to the effective use of most telecare equipment. While different agencies may organise their call handling or monitoring staff in different ways, the presence of someone who can interpret the information, provide reassurance, follow detailed individual protocols, and understand the basics of how equipment works is essential to ensuring the maximum benefit to the service user.

Appropriate response arrangements must also be in place, incorporating individualised response protocols which ensure the best possible response to the immediate need or situation. Traditionally this has relied on 'key-holders' – relatives or neighbours who, when contacted by the call centre, would call on the service user and solve the problem or contact services as necessary. Increasingly, in response to higher levels of dependence and more complex needs, agencies are deploying teams of trained carers, who can respond to an emergency and provide personal care, reassurance, or contact other emergency services as necessary.

In order for telecare services to have maximum impact on wider policy goals such as changing the balance of care, they need to be conceived as part of, and located within, local health and social care strategies for different client and patient groups. Service planners need to articulate how telecare developments will enhance home care and housing support services not as an 'add-on', but as an integral part of health and social care service options.

Risk and reliability

No equipment can be 100 per cent reliable forever, in the same way that no 'human' service is completely and consistently reliable. Equipment will come with a manufacturer's guarantee, but in the event of a fault an engineer will need to be called out, and there may therefore be gaps in service provision, even when monitoring is required '24/7'. Equipment which relies on mobile phone signals, internet access or landlines to transmit information will, on occasion, experience the lapses in service that affect these systems. To counter these risks, telecare services need to include backup, testing and business

To be effective, telecare requires an informed, skilled and personalised outcomes-focused assessment of needs and risk

continuity arrangements (although of course equipment purchased privately will not have these safeguards as standard).

'Interoperability' is a significant issue. This refers to the problems that arise when equipment developed by one manufacturer does not work with the call handling or monitoring system which is already in place, and which was made by another company. Progress has been made in resolving this issue, partly due to the introduction of a new (voluntary) British Standard⁸. However, interoperability remains a problem, especially when equipment does not comply with this standard.

It is very important that these issues are taken into account when care packages are being put together through the use of proper risk assessments and appropriate risk management arrangements.

Access and availability

This book includes examples of equipment that has the potential to contribute to the safety and quality of life of people in need. The examples have not been selected to promote the products of any particular company, but instead to raise awareness of what can be done and what is (or will soon be) available. Where a product is featured, details of the company that sells or manufactures it have been included (see page 38).

Companies specialising in telecare equipment are increasingly able to personalise their products to meet the needs of individual users. Furthermore, they recognise the importance of developing new applications from this starting point. Manufacturers would argue – with some justification – that the scope of what telecare equipment can do is limited by our imagination, rather than by the technology. The cost of equipment is falling, and public bodies now have procurement arrangements in place which should further reduce this cost. In addition, companies welcome contact with service users and professionals to help them understand needs which might be met through new applications.

Some telehealth equipment – blood pressure monitors, for example – can be bought on the high street, and this is a trend that is likely to increase as expectations and understanding of the potential of telecare increases. However, an important part of a telecare service is the response. There needs to be some way in which the information or alert generated by the equipment can be transmitted to someone with the skills and technology to generate a fast and appropriate response.

The major providers of telecare services are local authorities – increasingly in partnership with health authorities. Purchasing budgets are (or should be) available to enable practitioners to access equipment as part of a care and support package. Alternatively, service users should be able to purchase equipment using their individual budgets, or direct payments. In recent years budgets have been enhanced by government telecare support grants, and although some of these schemes may now be coming to an end, health and social care partnerships will continue to explore means of transferring resources so that telecare can develop further using the savings generated.

One consequence of the development in telecare services over recent years is that many authorities have recruited telecare coordinators, or have designated telecare 'champions' within local services. These staff can advise on availability and access, and should find these books helpful in their task of promoting the use of telecare among different client and patient groups.

Telecare equipment needs to be complemented by up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols

2: Assessment

An effective and efficient outcomes-focused needs assessment is essential if the potential of telecare is to be maximised. At its best, telecare forms part of an individual ('personalised') package of care and support. To achieve this, individual needs must be identified and telecare then considered as part of the potential personalised response.

General and specialist assessment of need

Throughout the United Kingdom, community care needs assessment is now conceived of as a multidisciplinary process^{9 10 11 12}. In Scotland, much work has been done to encourage the use of 'shared assessments'¹³ which gather core data on each individual (such as their name, age and ethnic group) along with information on physical, psychological, spiritual, and physiological needs. The process involves skilled interviewing to elicit what the person's needs are, and what their perception of those needs is at that time. There is an opportunity for a relative or close friend who is a carer to contribute – with the permission of the person. The assessment concludes with a summary of needs, followed by proposals for meeting them immediately (where necessary) and/or as part of a planned programme of care. (This will be dependent on resources being available and on eligibility criteria.)

The possibility of utilising telecare should be introduced during the assessment phase. Just as the person's need for home care, aids or adaptation, counselling or day services is considered, questions in the assessment form ought to trigger a discussion of telecare. During the assessment itself, it is essential to explain what telecare is, using language the person will understand and can relate to. One approach is to start with the (universally familiar) community alarm service, then move to a general discussion of environmental monitoring equipment (flood and smoke detectors for example), before moving on to personal safety and health monitors, where appropriate. At this stage the assessor will be considering the potential contribution of telecare in general terms, as well as introducing the concept to the person and their carer(s).

In some areas, a 'core package' is offered to anyone with community care needs. This might consist of a community alarm and smoke and flood detectors, along with a security device for the front door. Increasingly, in new or refurbished supported or sheltered housing schemes, such equipment is installed routinely. Opinion is divided on whether such an approach is cost-effective or not. Be that as it may, it does not obviate the need for individual needs assessments which will ensure that any additional equipment will meet identified needs.

All assessment documentation should therefore include a section prompting the assessor to consider telecare as part of the total response. It is also important that the assessor has access to information leaflets detailing the range of

At its best, telecare forms part of a personalised package of care and support.

telecare that is available locally, what it is for and who is eligible – along with any costs which need to be met by the service user.

If the assessor believes that telecare can form part of the response and the person agrees, a more detailed assessment is then required. This should include the precise combination of devices which can best meet (in combination with other services) the person's needs, as well as clarifying issues around installation and response. This stage is often referred to as the 'specialist assessment'.

Specialist assessments

This secondary assessment stage is designed to personalise the provision of telecare by identifying items of equipment that appear to best meet the person's needs. At this stage additional factors – such as the design of the property and the availability of telephone lines, wireless networks and mobile phone signals – will need to be considered. The person's familiarity with electronic equipment will also be taken into account, along with any other telecare equipment already installed. In addition, their routine (for example when they like to go to bed and their sleeping pattern) will also be recorded to ensure that the equipment supports the lifestyle and degree of independence they want. Finally, the integration of the equipment with the rest of the support package, and the need for and availability of a response, will all have to be detailed.

There is no 'best' way of carrying out a specialist assessment. How it is carried out, and by whom, is likely to depend on local arrangements. In some areas, a telecare 'champion' will have been identified within the community care team. This person will have received additional training in telecare and regular updates on the range of equipment available. One of their responsibilities will be to undertake this specialist stage of the assessment, or perhaps to supervise and guide other team staff when such an assessment is needed.

In other areas this task is carried out by a dedicated telecare service. This group will include staff who carry out the call handling, monitoring and installation functions, and they will have links to any response service. The manager of the service, or a designated person, will be asked to take forward the specialist assessment and carry out any installation that is necessary.

Risk assessment

Risk assessment is a critical component of a good needs assessment. It takes into account the degree of risk experienced by the person, thereby identifying ways in which telecare can assist in the management of risk (by the person themselves, as well as by services). It includes risks in the home as well as outside. These may include risks:

- of fire if the cooker is left on
- of flood if the bathwater is left running
- of scalding in over-hot bathwater
- of unwelcome visitors
- of getting lost
- of harassment
- of hate crime

Shared assessments gather core data, such as the person's name, age and ethnic group, along with information on physical, psychological, spiritual, and physiological needs.

The most basic equipment, such as flood, smoke and carbon monoxide detectors, reduces risk in obvious ways. For people with cognitive impairments (for example arising from brain injury) and some sensory impairments, going outside and travelling can be particularly risky. If the nature of such risks is identified, then appropriate equipment can be selected. This process is illustrated in later sections of the book.

While telecare can be important in the management of risk, it cannot eliminate risk completely. No equipment yet devised is 100 per cent reliable. Routine testing and maintenance (for instance battery changes) are essential to maximise reliability. Even so, malfunctions can occur. Service users – or more often their friends, children or grandchildren! – may inadvertently trigger or disable alarms, and monitoring centres will not always be aware of this. So it is important to allow for reliability and human error in any risk management plan.

Using telecare to enhance assessment

Some companies have developed equipment which can log detailed information about a person's movement, lifestyle and routines within their home. This is used for needs and risk assessment purposes, as distinct from safety. An example is 'Just Checking'¹⁴, a portable activity-monitoring system designed for people with dementia (although not necessarily limited to that group). Small wireless movement sensors are triggered as the person moves around their home. These generate an activity chart which can be accessed via a secure website. This very detailed timed data can provide a much more accurate picture of a lifestyle than is possible from conversation with a person with cognitive impairment, or from carers who do not live on-site. Support, protection and care arrangements can then be targeted more accurately in a person-centred way.

Carers' assessment

In Scotland there is now a duty to offer informal carers an assessment of their needs arising from their caring responsibilities. This focuses on how they can be helped to sustain their contribution to the care of a person in need¹⁵. Research has confirmed the extent to which telecare can reduce pressure on carers; support them in their caring role; increase peace of mind about the safety and wellbeing of the person they care for; and enable them to sleep better¹⁶. It follows that a good carers' assessment will include consideration of the potential of telecare to indirectly benefit carers by helping them continue to care.

Recent research confirms, however, that many carers are unaware of the availability of telecare. It cannot be assumed that carers – especially 'new' carers – will be aware of the possibilities telecare offers. Equally, carers will have their own anxieties, and perhaps guilt, about using technology. They may be concerned about its reliability or whether they will understand it and be able to make it work. These issues will be considered in more detail in later chapters of this book. At this point it is important to emphasise that information needs to be made available to carers, and that where a carer's views are sought at the needs assessment stage their perspective and needs should be included and recorded.¹⁷

Research confirms that many carers are unaware of the availability of telecare.

3: Principles, rights and ethics

The previous chapter described the importance of carrying out a careful needs and risk assessment before introducing telecare. However, while good assessment will ensure that the use of telecare is person-centred and needs-led, it will not necessarily answer the question of whether telecare is 'right' for an individual.

As an example, consider the needs of a person with Down's syndrome who is in the early stages of dementia. The assessment process may indicate that a GPS-enabled wristwatch could reduce the person's exposure to risk when she is away from home. It will enable her carers – and a control centre – to pinpoint her at any time so that they can organise help if she becomes lost or experiences harassment. But the device could also be used to restrict her freedom to go where she pleases, which is a fundamental human right. The telecare device could be perceived as a kind of electronic tag, and this has associations with surveillance and the criminal justice system. Seen in this light, the ethical questions associated with telecare are more sharply exposed.

It may be difficult to comprehensively establish the needs and risks of a person who could benefit from telecare, whether they have dementia, a brain injury, or significant sensory impairment. To carry out an effective assessment, a system like 'Just Checking'¹⁸ might be introduced to their home on a temporary basis. This will provide comprehensive data on the person's movements and routines, including eating, sleeping and toileting. Although the resulting assessment will be very well-informed, this does not necessarily justify the invasion of privacy that is also involved. Similar dilemmas arise with the use of systems such as Betavista which allow control centre operators to see the person in their own home (albeit when an alert is triggered), as well as talk to them on a phone line.

Ethical dilemmas such as these should be considered using the case studies featured later in this book. The purpose of this chapter is to briefly describe an ethical approach to telecare, summarise some principles which need to be considered when decisions are being made, look at the relevant legislation and provide some hints for practice.

It is important to stress four things at the outset:

- each person's needs, choices and beliefs must be a fundamental consideration in any decision
- there are few absolute 'rights and wrongs' which can be universally applied to every situation
- ethical issues are not unique to telecare. Indeed, the principles, values and legal obligations discussed here apply to other care and support settings
- no one acts in a value-free or value-neutral way – we all have our value positions. The important issue is understanding these, articulating them as necessary (particularly to service users and carers) and

This chapter describes an ethical approach to telecare and includes an overview of the relevant legislation and some hints for practice.

understanding and thinking through any conflict that may emerge with the values of others, particularly service users and carers

Personal value systems

We all take up value positions and have opinions on issues like the smoking ban, how children should be disciplined and capital punishment. Some people consider these issues to be 'common sense' or 'obvious', but in practice they are complex. Our personal values are influenced by the way we were brought up, our education, the apparent values of our community and by our life experiences. For those working in care and support services, there are also our professional values. These are often expressed through codes of practice¹⁹ and feature prominently in our professional education at every level. As a result we learn – and try to integrate into our practice – core values such as a commitment to confidentiality, treating people with respect, maintaining dignity and individuality, and challenging racism, discrimination and injustice.

It is important that practitioners are aware of these values, and how they come to be part of their own value system. It is also important to appreciate that they may not always be shared by individual service users and carers, with the resultant need to resolve conflicts that arise from different value positions.

Principles

Some writers have developed statements of principles, or ethical theories, which can help ensure that the use of telecare is ethically sound. For example, Bjørneby et al (1999)²⁰ have proposed these principles:

- **autonomy** – people should be able to decide what they want to happen or be done to them
- **beneficence** – we should try to do good to the people we care for
- **non-maleficence** – we should try to avoid doing people harm
- **justice** – people should be treated fairly and equally

In addition to these principles, Bjørneby suggests that the perspectives and views of all those involved in the service should be sought in relation to both its implementation and the likely impact of its non-implementation.

Kemshall and Pritchard (1997)²¹ highlight the values and rights which they believe underpin community health and social care services. These include:

- a commitment to ensuring that all users and carers enjoy the same rights of citizenship as everyone else in the community, with equal access to service provision, irrespective of gender, race or disability
- a respect for the independence of individuals and their right to self-determination, including taking risks, and minimising any restraint on that freedom of action
- a regard for the privacy of the individual, intruding no more than necessary to achieve the agreed purpose
- respect for the dignity and individuality of every user and carer
- to maximise individual choice in the type of services on offer and the way in which those services are delivered

When making decisions about telecare, maintaining respect for the independence of individuals and their right to self-determination – including taking risks – is essential.

- a responsibility to provide services in a way that promotes the realisation of an individual's aspirations and abilities in all aspects of daily life

Cox et al (1998)²² describe a set of core values that should be incorporated into any person-centred service designed for someone with dementia:

- that the person using the service should have maximum control
- that real and informed choice should be a key part of any service
- that people who use services should be valued and respected as unique individuals
- that continuity of care is built into service delivery in a way that keeps the person in touch with their past and present
- that the person is not discriminated against on the basis that they have dementia or because of any other differences, and that they receive their fair share of good quality and appropriate services

These values and principles provide the basis for rules of practice that will ensure an ethical approach.

The law

In Scotland, three important Acts of Parliament have been passed since 2000: the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003; and the Adult Support and Protection (Scotland) Act 2007²³. In addition to sharing a common purpose of protecting the rights of vulnerable people, these uphold a common set of principles: that any intervention must be intended to provide a benefit to the person which could not be reasonably obtained without that intervention AND that this is the 'least restrictive' option available. All three Acts also include a requirement to consider the person's views, along with those of significant others, like carers and family.

Capacity and consent

There will be many occasions when the introduction of telecare raises issues of capacity and consent. The assessment process may indicate the presence of significant risk that telecare (in conjunction with other services) has the potential to reduce. Despite this, the person may refuse the service or be reluctant to accept it. This might be because they disagree with the perception of the risk and/or want to retain the right to choose the way they live.

When working with people who may benefit from telecare but also lack sufficient capacity to make decisions about risk and quality of life, there may be justification for overruling these fundamental human rights. However, these are very significant judgements which should be made carefully and legally. It may transpire that a person's capacity is not impaired after all, but instead their means of communication, or ability to communicate, has not been properly considered. This is generally apparent when the person has a hearing or speech impairment, or perhaps has had a stroke, but may be less obvious when the person has dementia or a learning disability.

Where decisions are made on behalf of an individual who lacks the capacity to make choices for themselves, the course of action should be time-limited,

There will be many occasions when the introduction of telecare raises issues of capacity and consent.

regularly reviewed and limited to the particular services and decisions under consideration. Such decisions should never be considered as final or permanent.

Policy and procedures

Individual agencies will have policies, procedures and guidelines in place which ensure that staff remain within the law when delivering services – including telecare services. Implicit in these are the values of the agency, and of the community that it seeks to serve. For instance there will be commitments to equal opportunity, privacy, dignity and confidentiality, alongside procedural commitments to legality, cost-effectiveness and quality.

It is vital that practitioners are aware of these procedures and follow them. In the context of this chapter, practitioners should also be alert to conflicts between the values of users and carers and the values of their agency. These issues are often encountered in the area of risk and personal safety. Agencies have a duty of care, and in some cases their policies and procedures may conflict with the aspirations or expectations of the user, or their carer. For instance, procedures may prioritise the reduction of risk, as distinct from the freedom of someone to take risks and to make their own decisions. Practitioners need to be alert to these conflicts, and to make them explicit to users, carers and their own agency management. They must also ensure that the resolution of the conflict is recorded accurately and transparently.

Practitioners need to be alert to conflicts between the values of users and carers and the values of their agency.

Practice guidance

In summary, the following guidance is suggested:

- be aware of your own personal and professional value systems – and how these might conflict with the person you are working with and their carers
- be aware of the procedures of your agency, particularly those which are designed to protect the person's right to choose, to dignity, to privacy and to confidentiality
- ascertain as fully as possible the views of the person, their carers and other staff working with them. Do you understand what they are saying to you?
- are there issues of capacity to consent? If so, what are the legal issues around overriding their right to choice and consent?
- in what ways might the telecare solution limit this person's freedoms and rights? Is there an alternative which does not challenge their right to choose?
- how are the decisions to be made recorded? Has a record been provided to everyone who should have one? When is the decision to be reviewed?

4: Telecare and physical disability

This chapter describes how telecare can help in the support and care of people with complex physical disabilities, and some long-term conditions. There are descriptions of the equipment that is available and a number of case studies. Where possible, photographs of the pieces of equipment referred to have been included. Numbers identifying pictures also link in to manufacturers' contact details on page 38.

Definitions: whom are we talking about?

The Disability Discrimination Act defines a disabled person as 'anyone who has a physical or mental impairment that has a substantial and long-term adverse affect on his or her ability to carry out day-to-day activities'. Audit Scotland defines long-term conditions as 'those that cannot at present be cured but can be treated and controlled over a long period of time by medication and other therapies'²⁴. The National Service Framework for Long Term Conditions uses the following definition: 'any ongoing, long-term or recurring condition that can have a significant impact on a person's life'.

Physical disabilities and long-term conditions can encompass:

- loss of limbs
- neurological conditions such as multiple sclerosis, stroke, motor neurone disease and muscular dystrophy
- spinal injury
- brain injury
- medical conditions such as heart disease, respiratory disease, diabetes and arthritis

Characteristic needs of this group

Typically the needs of this group will include:

- physical and practical support with activities of daily living
- physical and practical support to engage in education, work or leisure activities
- rehabilitation
- compensation strategies and adaptation to changes
- awareness of available services and provision, including equipment, housing adaptations, benefits advice and rehabilitation services
- quick and easy access to services as needs arise
- regular monitoring and review of their condition and changing needs

- knowledgeable case management and coordination between all services and service providers
- proactive management of their disability and/or condition
- maintenance of their independence and quality of life
- involvement in decision-making regarding their care and rehabilitation provision
- being as self-managing as possible

The majority of people with moderate to severe physical disabilities, and/or long-term conditions, will be known to, and receive services from, health, social work, housing and education organisations. Increasingly, these organisations are working together in partnership. There may also be input from informal carers and the private and voluntary sectors.

Telecare can help individuals carry on living in the home of their choice, as opposed to moving to an adapted property or care home.

Meeting people's needs in the community using telecare

Telecare can help to meet the needs of many people with a physical disability or long-term condition, including aspects of self-management, independence and safety. Sometimes these needs can be met using telecare alone, but most often telecare will be provided in conjunction with other services.

Telecare can help individuals carry on living in the home of their choice, as opposed to moving to an adapted property or care home. It is sometimes said that equipment constitutes approximately five per cent of the provision of support and the remaining 95 per cent is made up of the services that complement the equipment. In many cases this will be an overstatement, but it does highlight the need to think of telecare as complementary to home-based services, not an alternative solution.

How can telecare enhance quality of life and independence?

Quality of life is multidimensional and may include the following elements:

- physical well-being, including good mental and physical health
- material well-being, including income and standards of living
- social well-being, including neighbourhood, friends and inclusion
- emotional well-being, including mental health, relationships and family life
- development and activity, including employment, education and leisure

All these elements impact on each other, and change in any one area is likely to have an effect on the others. Research has shown that people who have limiting or non-limiting long-term conditions are more likely to feel negative about their quality of life and, more specifically, their health (Scottish Government 2007)²⁵.

Choice, control and independence are three further, linked, components of quality of life. The majority of people value the degree of choice and control they have over the way they live their lives. Services that are inflexible can result in disabled people having very limited choices about when and how they do things. In its *Report of the Disability Working Group (2006)*²⁶, the Scottish Executive described independence as follows:

Independent living does not mean doing everything for yourself. It means having choice over who does what on your behalf, and control over when and how. Ultimately it means having the same choice and control over your life as non-disabled people do.

Used properly, telecare can and does help to return or introduce choice and control into the lives of people with many types and degrees of disability, enhancing their independence and quality of life as a result.

Examples of equipment: safety at home

This has the potential to benefit people who:

- are frail, isolated or vulnerable
- have a medical condition that may necessitate assistance in an emergency
- live alone or spend long periods of time alone
- have dependants within the household

Examples of devices in this category include:

Secure door entry systems 1. There are several types of these. The most common allows the individual to control the door via an intercom, using a remote control to unlock it if they want to let the person in. This enables them to stay at home alone safely but unlock the door if they wish. A second type of door entry system is designed for people who use wheelchairs. This uses a timed mechanism that allows secure entry and exit from the building, and incorporates a closing and locking mechanism. A third type of door entry system can be accessed by someone outwith the home, such as a parent, child or carer. They can then 'manage' the answering of the door remotely.

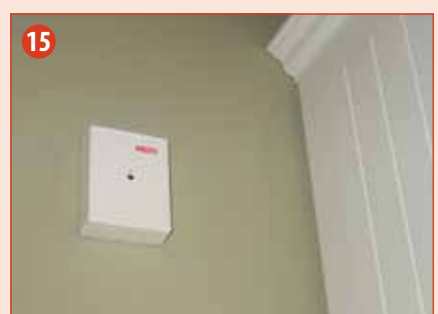
Community alarm services provide a reliable 24/7 response to people who live alone and are at risk. They may be appropriate for people who:

- are at risk of falling and may be unable to get up
- live alone and are vulnerable
- have a disability or medical condition that may require urgent assistance

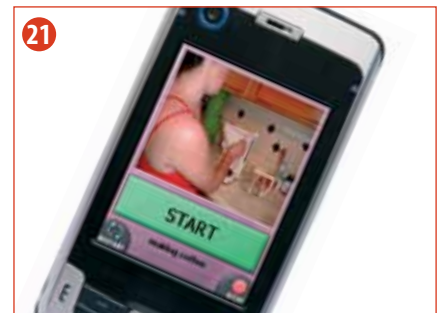
The system uses a landline connection to a contact centre and involves two-way communication with this centre. Contact centre staff determine what the problem is and inform the community wardens, a response team, carers, or a 'key-holder' who can visit the person if necessary. Community alarm services can also be linked to an **environmental control system 2** (a sophisticated remote control unit that can perform tasks such as operating lighting, home appliances, door entry and telephone), making them suitable for people with complex physical disabilities. Community alarm services can include a pendant which the person wears around their neck **3** or wrist **4**, and which they can press to summon help if they fall or cannot reach the phone. Bogus caller alarms use the community alarm service to call the police when the person presses the alarm.

Used properly, telecare can return or introduce choice and control into the lives of people with many types and degrees of disability

Environmental alarms, detectors, monitors and reminders. These include smoke detectors **5 6**; gas detectors **7**; carbon monoxide detectors **8**; PIR movement detectors **9**; flood detectors **10 11 12**; door contacts **13**; cooker shut-off devices; sensory alarms, for example smoke detectors designed for people with severe hearing impairments **14**; and temperature monitors (designed to detect abnormally high or low temperatures) **15**.



Other devices include bed/chair occupancy monitors **16** **17**, seizure monitors **18** and tilt/fall detectors **19** **20**.



A variety of **reminder devices** are available. These include voice enunciators, which use a PIR movement detector **9** to trigger a pre-recorded message. They can be placed in a strategic location, such as in a person's hall near their front door, providing an audio prompt such as "Remember to take your keys" when triggered. Cognitive support devices **21** are mobile devices that can be programmed to provide visual and auditory information such as prompts, reminders, wayfinding or sequencing information. A range of medication reminder devices **22** is also available. These use an alarm as a prompt and can help ensure that medication is taken at the same time every day. Some types are incorporated into a wrist watch **23**.

Many of the above can be linked to a call or control centre, or responded to within the home/care setting by family members or carers. Health/symptom monitors **24** – for example those that monitor blood pressure or blood sugar – can also be linked to a surgery or community nurse.

Case study 1

Mr G is in his late 20s and has epilepsy. There is no pattern to his seizures (tonic-clonic) and they occur with little warning. He lives with his parents and works as a gardener at a day centre. On two occasions last winter Mr G was found unconscious in the grounds of the day centre during cold weather. He had no recollection of how long he had been there. He was unable to alert anyone and his colleagues were very concerned for his safety. He was in danger of losing his job.

Solution. Mr G was provided with a community alarm unit **25** and tilt/fall pendant **26**. The alarm unit was installed at the day centre where he works. Now, if any alerts are triggered, the call centre phones the day centre manager and her staff can respond. If there is no immediate response, the mobile emergency care wardens attend the call. At home, Mr G now has a seizure monitor **27** (which he uses at night) that is linked to the call centre. Staff are alerted if he has a seizure and an appropriate response protocol is followed.

Outcome. Mr G's job is now secure and his safety has been enhanced. His colleagues are now less anxious about him. Details of any calls generated by the seizure monitor are logged at the call centre and fed back to the professionals involved in Mr G's healthcare. The information allows them to manage his medication optimally.



Case study 2

Mrs S is 75 and lives in an upstairs flat with her daughter, who works full time. Mrs S was independent about the house until she had a stroke. Since then she has been left with some weakness on her right side which affects her balance and results in falls. She has also become a bit forgetful, and has flooded the bathroom twice and burned a number of pots in the kitchen. There are concerns about her safety and her ability to continue living with her daughter. Mrs S often gets up during the night to use the toilet, and her daughter's sleep is being disturbed as she is afraid Mrs S will fall. She in turn is getting frustrated and annoyed at her daughter's 'interference'.

Solution. Mrs S was provided with a community alarm unit and tilt/fall pendant **28**. She was also referred to a falls management programme. Flood, smoke and gas



detectors were installed in her flat. Passive infrared (PIR) movement detectors were placed by her bed and along the route to the toilet. These switch lights on in sequence as she moves through the house. Her daughter was given a pillow buzzer **29** that vibrates when the PIR detectors are activated. This lets her know that her mother has got up, and means she can listen and check she returns to bed safely. The contact centre responds to alerts during the day, and as Mrs S's downstairs neighbour is a key-holder, she can intervene quickly if necessary (for instance if the flood detector has been activated).

Outcome. Mrs S can continue to live safely with her daughter, and her daughter can carry on working.

Examples of equipment: safety away from home

In order for telecare to enhance a person's safety when they are away from home, a number of criteria must be met:

- simpler strategies should be explored first
- the person must have the will and ability to use the equipment
- the equipment should lead to an improvement in the person's quality of life and/or decreased dependence on formal or informal carers
- whoever is acting on behalf of the person should have a good insight into the nature of the problem

Computer and mobile phone devices

GPS location devices **30** can communicate a person's location to secure servers. Their position and other data can be found by looking on a website, or the information can be transmitted by SMS (text message) or email. An alarm or alert may be raised, either by the user of the device pressing a panic button, or by the system itself. Alerts can be triggered if the user moves out of or into a specified area (a 'geofence') or if they are moving above a certain speed.

30



Case study 3

Polly is 19 and autistic. She lives with her parents and brothers. She is keen to be as independent as possible and likes to go out and call on her friends who live locally. Her parents are also keen that she learns to be as independent as possible. Polly becomes easily distracted when she is out, and sometimes wanders off, causing great concern to her parents. On a few occasions she has been harassed by young men in the neighbourhood, causing her considerable distress.

Solution. Polly was given a PDA **31** **32** (mini computer) loaded with cognitive support software. Her parents and teachers can programme this easily, giving her visual and audio prompts to carry out activities at specific times (ie 'Time to go home for dinner'). The PDA also has a panic button, and if Polly presses this she hears a message with instructions on what to do if she finds herself in

31



Case study 3 (continued)

trouble. Because the PDA incorporates GPS, Polly's location can be pinpointed via a secure website if needs be.

Outcome. Polly can go out locally with her friends, supported by her PDA which prompts her to return home at set times. As a result, her parents are less anxious about her going out alone. There are additional options to use the technology to support Polly at college. For instance, she can be sent prompts to change classes, and there is a 'notes' function where parents and teachers can leave messages for her.

Case study 4

Kevin is a 38-year-old man who lives with and helps to care for his elderly father. He was previously very independent, and when not helping his father he had an active social life, meeting his friends regularly. Kevin was formerly an avid games player which required memory, concentration and attention. He has diabetes which is controlled with medication. Two years ago he was the victim of an assault, following which he was left with a brain injury and weakness which affects his walking (he uses crutches). This has affected his memory, concentration and ability to sequence some tasks. Kevin has made strenuous efforts to compensate for his problems by using reminders on his mobile phone, notebooks (which he tends to lose), a diary and computers. However, he still experiences problems when he leaves the house as he can't take all of these prompts with him. He has also been forgetting to eat or take his medication for his diabetes. As a result he has lost several stone in weight and his diabetes has become out of control. His mood has become very low and he has stopped going out.



Solution. Kevin was provided with a PDA **31** **32** and cognitive support software. This allows him to set audio-visual prompts, reminding him to eat and take his medication. He can also add details of any hospital appointments for him and his father. In the 'tasks' screen Kevin has downloaded the rules for his game-playing, which consists of several pages of detailed information. The PDA can also take a SIM card and double up as his mobile phone.

Outcome. Kevin now has a means of supporting his cognitive problems and, as this is portable, he can use it outside the house. He has regained weight and his diabetes is under control. In addition, he has resumed his game-playing and goes out to meet friends again. As a result his mood has improved and he feels he has some pleasure in life again.

Examples of equipment for managing the home environment

Equipment for managing the home environment 33 34 35 has the potential to benefit people who:

- have complex physical disabilities
- have the will and ability to use the equipment
- have needs that can't be met with simpler equipment



Case study 5

James is 30 and lives with his wife who works full time. Last year he fell down a flight of stairs and sustained a spinal injury. After being in hospital for a year, he moved into a wheelchair-adapted house. He is tetraplegic, with no movement in his legs, no function in his right hand and only very slight movement in his left. Before the accident, James worked full time as an undertaker, a job that he really enjoyed. He and his wife had a busy social life with family and friends, and James was a keen footballer. With his limited movement he is able to operate an electric wheelchair and has a touch-screen mobile phone which he can operate using his knuckle. However, he has great difficulty reaching and operating the controls for most household appliances and is unable to open and close doors. When alone, James is confined to the house unless someone is there to open doors for him. Additionally, he has problems with sensation and develops pressure sores easily. As a result of his spinal injury, he also has a condition that necessitates emergency help and medication. He is very motivated to be as independent as possible and to get out and about as much as he can.

Solution. James was provided with an environmental control system. This incorporates a main controller (essentially a very sophisticated remote control unit) which operates a range of devices using infrared or radio frequencies. The controller scans through programmed options and provides visual feedback. The options have been adjusted to meet James's needs.

Using the main controller, which is attached to his wheelchair, James can now operate:

- a full door entry system including intercom, door release and door opener
- lights and lamps in his bedroom and the living room
- all of his home entertainment in the living room and bedroom
- his profiling bed
- his community alarm
- his computer
- a temperature control unit

Outcome. James can spend long periods of time at home alone. He can also go out when he wishes, knowing that the door is locked securely behind him. When home he can choose what he wants to do – for instance watch TV or use the computer. Should he feel ill, he has a means of accessing help quickly. If he is unwell or has pressure sores, he can still operate all the devices described from his bed. James now has some independence and choice and his quality of life has improved. His wife can continue to work in the knowledge that he can manage some things independently and his safety is ensured.

Examples of equipment to help people manage a long-term condition

Long-term medical conditions include heart disease, respiratory disease and diabetes. Equipment to help manage conditions such as these has the potential to benefit the following people:

- those who have more than three unplanned hospital admissions per year
- those who would benefit from regular monitoring of their condition
- those who are motivated to become self-managing
- those who would benefit from early supported discharge



Telehealth and telecare devices can be used to take measurements including ECG, blood pressure, pulse, oxygen levels, respiratory function, weight, blood sugars ³⁶ and blood clotting. The devices are located in the person's home and clinicians can log on to a secure website to collect the results. Providing feedback to people about their long-term condition can assist with self-management. Furthermore, the results of different users' readings are triaged automatically, flagging up to clinicians those who need the most urgent medical help and those who are successfully self-managing.

Case study 6

Mr D is 64 and lives with his wife. He had to give up work as a mechanic several years ago when he was diagnosed with heart disease which severely limits his activities and his life in general. He is considered to be uncooperative with his treatment and medication. Mr D has had two hospital admissions in the last three months. Each lasted for several days and he does not like being in hospital.

Solution. Mr D was provided with a telehealth monitoring system ³⁷. This operates via a unit in his home, and includes attachments which can take a variety of measurements, including blood pressure (BP), heart rate and weight. Using the unit, Mr D checks his BP, heart rate and weight daily, submitting the results to a secure website via broadband. His results are received by a clinician, along with those of many other people using similar systems. An inbuilt triage system flags the results as either red, amber or green so that the clinician can specifically target those people whose measurements give rise for concern.



Case study 6 (continued)

Outcome. Mr D is taking a more proactive role in managing his heart condition, even instigating calls to the clinicians when he notices that his measurements are changing. Because fluctuations in his condition are being identified quickly, his medication can be adjusted as necessary. As a result, Mr D avoids unnecessary hospital admissions and is much happier being treated at home.

Issues for carers and for care and support staff

The benefits of electronic assistive technology are potentially significant for carers too. Simple solutions can provide a great sense of relief to family members and carers. With appropriate technological support, people can remain safe both in their own homes and outdoors. Technology can enable them to enjoy higher levels of independence, with the result that they need less time and support from carers. Devices such as pagers and alarms mean that individuals can call on assistance more easily, if required, and this provides a degree of security for relatives and carers. As a result, relationships are less likely to be strained.

However, there are still a number of hurdles to overcome before telecare can be deployed effectively. Firstly, carers may not be aware of the availability of telecare to support them in their caring role, or appreciate its potential. Secondly, it cannot be assumed that the carer of a person with a physical disability will be supportive of the use of technology – or that they will monitor its use. Likewise, partners and older children may have concerns about adaptations to laptops, mobile phones and domestic equipment – perhaps because of inconvenience, anxiety about change, reliability or stigma. Older parents in particular may have had different experiences of caring, often fighting for services at a time when they simply did not exist. As a result, they are often more reluctant to seek help or support (Magrill 1997)²⁷, and this can be reflected in a reluctance to work towards more independent living for their son or daughter. They may also be anxious in case telecare is being suggested as a cheaper alternative to staffed support arrangements that they have had to fight for. These views must be taken into account before bringing new technology into the family home.

To be effective, practical support within or outwith the home needs to be part of a long-term care package that is regularly reviewed and incorporates the needs of the person with a physical disability or long-term condition, along with those of their carers. For consistency, respite carers and those offering short breaks need to be aware of any use of technology by the person. Implementing telecare effectively is likely to require clear explanations for carers, as well as for the person with a physical disability.

Carers and care staff also need appropriate training and support in the use of telecare. Although use of mobile phones and the internet is widespread, it should not automatically be assumed that staff or family members will be familiar with them. Staff may have no desire to use these technologies themselves, so may have difficulty incorporating them into their daily work. What may be seen as a reluctance to support a person with a disability may in reality be due to feelings of uncertainty about the technology which need to be acknowledged. These issues can be overcome by support and training. In some cases the carer or staff-member may learn alongside the person with a physical disability or

Carers and care staff also need appropriate training and support in the use of telecare.

It is important that more than one staff or family member is familiar with any technology that is introduced.

long-term condition, which can prove beneficial for both. Training and support for staff are essential, and should form part of personal development plans which will ensure that this area of work is recognised and acknowledged. Additionally, clear lines of accountability and reporting are needed. If necessary, job descriptions and person specifications should be expanded for both existing and new staff to reflect their expanded role.

It is important that more than one staff or family member is familiar with any technology that is introduced. There will normally need to be someone on shift at all times who is familiar with how each piece of equipment works. Equally, call centre staff need to be aware that the person they are responding to has a physical disability and understand any special communication and response arrangements (arising, for example, from hearing impairment or a particular cognitive impairment). These should be in the individual response protocol that is established at the time of installation. Discussing this plan regularly at team meetings will mean that staff are familiar with the issues they may encounter, rather than becoming stressed when they face a problem or receive a call. This is especially important in organisations where there is a high staff turnover or regular use of agency staff.

When telecare is first introduced, paid staff may have concerns about their job security and be fearful of being replaced by technology. Although the introduction of telecare may open up possibilities for new or different roles, this need not be at the expense of contact time and social interaction with people who have a physical disability or long-term condition – especially those living alone, for whom loneliness can be a very real issue. Instead, routine ‘supervision’ or check visits can be replaced by equipment, freeing up staff time for more worthwhile social interaction.

5: Training programme

This section contains content and a suggested timetable for a one-day training programme on how telecare can contribute to the care and support of people with complex physical disabilities and some long-term conditions. It may also provide a basis for a longer programme for specialist assessors or 'telecare champions' if combined with 'shadowing' experiences and visits to a control centre, response team, and contact with service users already experienced in telecare. Similarly, it may be of value to course leaders of qualifying programmes for social workers, occupational therapists and community nurses.

It is an outline programme which skilled trainers will need to adapt to the particular training needs and circumstances of local groups.

Aim

To support participants in the development of their knowledge, skills and understanding required to introduce telecare into individualised care packages.

Objectives

- to learn how telecare can contribute to the support of people with complex physical disabilities and some long-term conditions, and their carers
- to develop practice in needs and risk assessment, and care planning, so as to maximise the benefits of telecare
- to increase knowledge of the legal and ethical framework for good practice
- to understand the wider policy and strategic context for telecare

Timetable

9.00 Welcome and introductions

- domestic arrangements
- discuss agenda and clarify expectations of the course. Refer to the aims and objectives to confirm what the course can and cannot provide. Invite participants to discuss, briefly, with each other, their current knowledge and understanding of telecare, their perceptions and anxieties about technology, their expectations of the day, and their individual training needs

9.30 Definitions of telecare and telehealth

This could be a 'teaching' session with a presentation and handout based on the definitions provided in the introduction to this book.

Key learning points are:

- the meaning of terms such as telecare, telehealth, telehealthcare and an introduction to the 'generations' of telecare
- the lack of commonly accepted standard definitions, and the extent to which terms are interchangeable, and changing
- the speed with which technology is developing in all areas of our lives
- the effect of this on service user and carer expectations

In this session it will also be important to remind participants about the nature and impact of different sorts of disability, and so begin to explore the ways in which technology can support people with different conditions. Assuming that participants will already be working in the field of disability, the key learning points will include:

- being aware that the successful introduction of telecare depends on understanding the individual nature of a person's physical disability or long-term condition
- being able to develop and use specialist communications skills if the disability has affected speech or comprehension
- taking a person-centred approach to care and support and encouraging higher expectations among the family and carers of the person who is being considered for telecare. This includes developing a proactive approach which engages the person in meaningful and enjoyable activities
- being open to new and changing ways of providing support

Gather together any thoughts and initial reactions at this stage without looking for conclusive ideas. Some of the definitions may be new to participants, and time is available to ask questions about these throughout the day. Reassure participants that they will have the opportunity to apply these to practice later.

10.15 How can telecare help support people with a physical disability or long-term condition?

This should be an opportunity for participants to see pictures of, and, if possible, actually touch and feel equipment. It is important to explain the kind of support needs for which pieces of equipment may be useful, and to talk through examples of equipment which may be in development but not yet available.

Local providers and suppliers may offer to put on a display of equipment, at no charge. If there is a local 'smart house' it may be possible to locate the training session there – or to organise a visit at the end of the day or at the lunch break.

Ask the group to look at the illustrations of equipment in chapter 4 and share their ideas about each item's uses and limitations. Participants may have additional valid suggestions about uses and limitations based on their own experiences. Ask the group to split into pairs and think about a person they know who may benefit from some of these adaptations or interventions, along with someone who would be unlikely to benefit from them.

10.45 Break

11.00 Case studies – telecare in practice

In this session, participants will look at a variety of different scenarios in pairs and think about what equipment would be useful. It is also important that they think through the implications – for example:

- what is the need that is to be met (the importance of careful assessment; avoiding simplistic solutions; not ‘just giving out bits of kit’)
- the different perspectives of the service user, their family and support staff
- differing attitudes to risk
- how telecare can supplement other kinds of support but is not intended to replace them
- the importance of maximising levels of independence and retaining personal skills
- promoting proactive self-management of long-term health conditions or disabilities
- encouraging/enabling individuals to remain in their own homes/communities for as long as is safely possible
- reducing unnecessary movement to alternative forms of accommodation, such as nursing homes, care homes and hospitals
- fostering a feeling of security for individuals and their families
- improving quality of life
- providing greater choice

Ideally, participants will share their own experience and ‘cases’ with colleagues. Handout A contains some additional case studies which can be used as an alternative, or in conjunction with participants’ own experience and those provided earlier.

12.00 The importance of good assessment

Bring participants back together as a single group and compare the ideas that emerged in the previous session. Encourage debate about how telecare contributed to the support of the individuals in the case studies in the following ways:

- draw out the importance of good assessment. Refer to the section on assessment in this book. If necessary, develop a handout or use an example of a local assessment tool
- make sure risk is considered, as well as need
- highlight the differing concerns and benefits as seen from different points of view
- bring any difficult issues into the open, such as staff reluctance or how carer concerns should be addressed
- highlight what the problem is and who the telecare is intended for. Are there consent issues, or differing perspectives on risk, need, capacity or consent?

13.00 Lunch

14 00 Telecare may be the solution ... but is it ‘right’?

This is an opportunity to discuss with participants the rights and wrongs of using telecare, looked at from their own perspective, as well as their employer's and professional perspectives. Chapters 2 (Assessment) and 3 (Principles, rights and ethics) may provide the basis for a short introductory talk. Alternatively, this could be an interactive session in which the following kinds of questions are posed:

- telecare can involve the monitoring of people's private lives. Is that 'right'?
- some equipment restricts people's freedom to do as they want or go where they want in order to 'protect' them. What is the right balance between risk and protection and how do we achieve it?
- telecare can be used to support a 'normal' lifestyle – getting up in the morning, going out during the day and going to bed at night. Is telecare being used to 'impose' a conventional lifestyle?

Stress that people with a physical disability or long-term condition should only have their movement restricted or monitored with permission, and where this complies with the law and care regulations. Discuss what permission means where there is significant cognitive impairment and talk through what the law dictates in this area. These issues can be discussed in the context of the case studies from the previous session.

Participants need to be clear about the legal constraints on this (and any other) part of their support service. They have a responsibility to make decisions that are both ethically defensible and legal. An approach based on individual assessed needs will always present ethical dilemmas which need to be resolved.

15.00 Policies, procedures, and strategy to support the use of telecare

This session provides an opportunity for participants to explore and gain a better understanding of local policy and procedures. It should include discussion of local assessment tools to ensure that participants understand when and how telecare can be introduced into the assessment process. Local procedures for accessing telecare, as well as for installation, testing and responding to call-outs, should be discussed and explained, along with charging policies and budgets.

It may also be useful to discuss local strategy. How does the use of telecare fit with local joint strategies for people with physical disabilities or long-term conditions? If time is available, it will be useful to look at the national strategy too and discuss how telecare can contribute to national policy goals such as Shifting the Balance of Care. (Resources are available on the National Telecare Development Programme website – www.jitscotland.org.uk/action-areas/telecare-in-scotland/)

16.15 Conclusions and evaluation

Ask the group if the discussions they have had during the afternoon have influenced the way they would now approach the case studies introduced earlier in the day. Do they now feel more confident about making a recommendation and supporting a person with a physical disability to make an informed choice about telecare?

Summarise and ask what the participants will take away from the day. The discussion could include areas of new technology and the potential for the future use of telecare and telehealth as a way of supporting people with a physical disability or long-term condition.

Handout A: Scenarios

Spilt into pairs and work through the following scenarios. Share your responses with the group once everyone has had the chance to work through the scenarios in pairs.

Scenario 1. Steven is 39 and has MS. He wants to continue living in his own home, but is wheelchair dependent and has limited use of his hands. Carers call in four times a day, but Steven spends most of his time alone. He wants to have control over as many aspects of his life as possible. His parents worry about his safety and ability to get help if he requires it.

How can Steven be supported to stay at home with the use of telecare/technology?

Scenario 2. Michael is ten and has muscular dystrophy and autism. He lives with his mum, dad and three siblings. He is wheelchair dependent and has weakness in his hands, particularly the left. Carers call in twice a day and Michael attends a school with enhanced support. He needs a consistent approach and gets upset at changes in his routine. In particular, he needs many prompts to help him work at school.

How could telecare/technology support Michael and his family at home?

Scenario 3. David is an 18-year-old man with mild learning disability and some minor physical disability. He lives with his parents and brother but would like to live independently. His parents are concerned about his ability to manage on his own, and in particular about his safety.

How would you assess David's abilities and decide which technology might be appropriate for him? How could you reassure his parents?

Additional resources*

For further information about telecare and the National Development Programme in Scotland, please contact the Joint Improvement Team via their website:

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

The website for the equivalent programme in England is:

<http://www.dhcarenetworks.org.uk/independentlivingchoices/telecare/>

Other websites

Information and general advice from the Disabled Living Foundation:

<http://www.livingmadeeasy.org.uk/telecare-167/>

Consumer reports on telecare equipment:

http://www.ricability.org.uk/consumer_reports/at_home/

Home Farm Trust is a national charity supporting people with learning disabilities and their families. For more information about what they call 'personalised technology' email personalisedtechnology@hft.org.uk or visit http://www.hft.org.uk/What_we_do/Assistive_technology

The AT Dementia website brings together information about assistive technology that has the potential to support the independence and leisure opportunities of people with dementia: <http://www.atdementia.org.uk/>

Information on assistive technology for people with dementia:

<http://www.atdementia.org.uk>

Telecare Services Association (TSA):

<http://www.telecare.org.uk>

Social Care Institute for Excellence – Dementia Gateway. This section of the website looks at the use of technology:

<http://www.scie.org.uk/publications/dementia/environment/assistive.asp>

Centre for Usable Home Technology:

<http://www.cuhtec.org.uk/>

Centre for Accessible Environments:

<http://www.cae.org.uk/>

Enable:

<http://www.enableproject.org/>

Dementia Services Development Centre:

<http://www.dementia.stir.ac.uk>

DVDs

Telecare – supporting Scotland: a different approach. DVD which includes seven 'digital stories' illustrating, in the words of users and carers, the impact of telecare. Available through

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

Telehealth in Action. Scottish Centre for Telehealth:

<http://www.sct.scot.nhs.uk>

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Supplier contact details

The images of equipment featured in this book represent a small subsection of the range currently available. The contact details below have been included to assist purchasers in assessing what is available from whom, but in many cases the same device is available from more than one supplier. The publishers in no way endorse any particular supplier or product. The lack of inclusion of a particular product does not imply that it is inferior to any device featured. Purchasers are responsible for researching the full range of products available and reaching their own conclusions about what is most suitable for them or their clients.

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